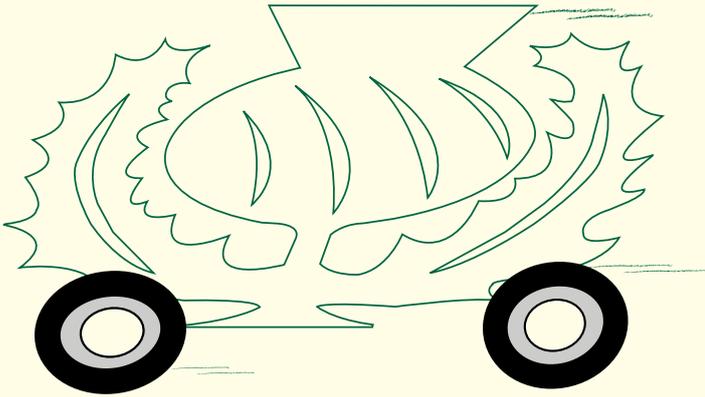


*Welcome to the SIGN
patient network update*



SIGN is moving !

From March 17th 2008 our new contact details are:

SIGN Executive
Elliott House, 8 -10 Hillside Crescent
Edinburgh EH7 5EA

Tel: 0131 623 4720 • Fax: 0131 623 4503

New SIGN publications

SIGN 99: Management of cervical cancer

This new guideline was published in January. The guideline covers:

- Presentation and referral
- Diagnosis and staging
- Surgery
- Non-surgical treatment
- Treatment during pregnancy
- Sexual morbidity
- Lymphoedema
- Follow-up

- Management of recurrent disease
- Management of complications in advanced disease
- Psychosocial care and support for patients and carers

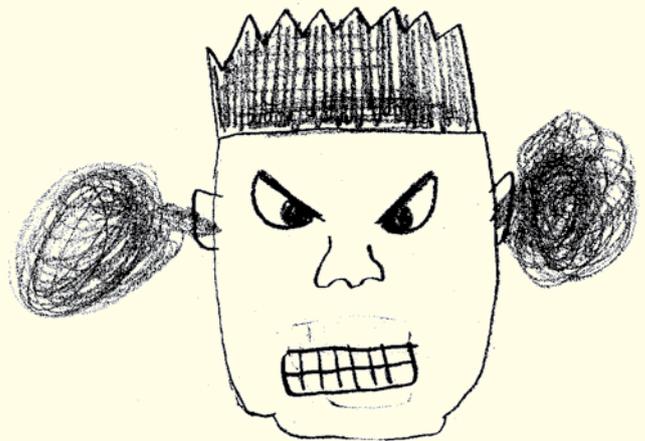
We would like to thank all lay representatives who were involved in the development of this guideline.

SIGN 98: Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders (ASD)

Two different patient versions of the ASD guideline will be published this month:

- Autism spectrum disorders (ASD): booklet for parents and carers
- Autism spectrum disorders (ASD): booklet for young people

There has been a significant amount of lay input into these two patient versions ranging from writing parts of the patient versions to commenting on the drafts. We also spoke to young people with ASD in Scotland and asked for their views.



The young people also took the time to provide us with fantastic illustrations for these booklets. We would like to thank everyone who contributed.

If you would like to pre-order copies of these new patient guidelines, you can request them by phoning 0131 718 5090.

SIGN goes public – the results!

Shop your way to involvement

In the last edition I mentioned that we were visiting shopping centres in Inverness and Livingston to create awareness of SIGN and encourage members of the public to become involved in our work. We had a lot of interest and enjoyed telling people about our guidelines, patient versions of guidelines and our patient network.

We were delighted to recruit 70 people to our patient network and we would like to welcome all newcomers to SIGN – you will know who you are! We feel that by going to the shopping centres we have reached a wide range of people who we would not have been able to involve via our usual methods.

I have had a number of enquiries from people who spoke to us at the shopping centres either asking for more information on our public involvement work, requesting specific patient versions of guidelines or asking if they can become involved in a specific piece of work.

This has been worthwhile and we will continue to use this type of approach to engage with members of the public in the future.

SIGN exhibition at Royal Infirmary of Edinburgh

We also took the SIGN stand to the Patient Information Centre at the Royal Infirmary of Edinburgh in January. We spent the day talking to staff and patients about our processes, clinical guidelines and patient versions of guidelines. Producing patient versions of guidelines is a new innovation for SIGN so it was useful to receive some direct feedback on them. Feedback included:

- Good idea – good to see patient info as well as main SIGN guideline
- Well advertised. Informative. Enthusiastic staff. Very helpful and it is good to see information being provided in plain English for both doctors and patients.
- Very nice people, also very helpful, all questions asked were answered, as well as help for the future. Glad I came in.



Photograph of Louise Phillips by Emma-Jane Harrington

We will be exhibiting at the Royal Infirmary again later in the year and we will keep you posted on this.

Perhaps you would like us to exhibit somewhere in your area? Can you help us organise this? If you are from an organisation, perhaps you invite guest speakers to talk to your staff or service users? Would you like someone from SIGN to come along to talk about our work? Please get in touch if you would like us to organise this.

Discussion day at SIGN with Santa's little helpers!

SIGN lay representatives took part in a Christmas themed discussion day in December to have input into patient involvement activities we plan to carry out this year. As well as being subjected to SIGN staff wearing flashing Santa hats and Christmas music, lay representatives worked together to discuss how we could improve two areas of patient involvement at SIGN.

1. Patient/public involvement section of the website – lay representatives discussed how we could make this more interactive and what type of information should be available. Some ideas included:
 - Using the website to recruit patient/carer representatives
 - Providing the opportunity for lay representatives to complete on-line surveys

- Video clips of patient representatives and clinicians explaining how important patient/public involvement is to the NHS
- Patient/carer representative experiences of various conditions
- Improving graphics to make it interesting and appealing
- Advertising the SIGN website in public places to let people know it's there.

2. Raising awareness of patient information – discussions took place around how we could make our information more appealing to the target audience and how SIGN and lay representatives could help promote this information. Suggestions included:

- Providing hospitals and GP surgeries with a specific SIGN rack for patient information/promotional material
- Need for better graphics
- Providing bookmarks for distribution to libraries, colleges etc
- Advertising in health board and voluntary organisations' newsletters and bulletins
- Possibility of lay representatives promoting SIGN information within their organisations



All suggestions have been taken on board and we will make every effort to implement them throughout the year. We would like lay representatives to continue to be involved with the development of the website. A few people on the day volunteered to participate in a short-life working group to take this forward this year. Watch this space!

We need your help!

Become a guideline development group member

I mentioned in the last edition, that we will be reviewing a number of our guidelines this year. We still require lay representatives to join the guideline on **the care of patients with chronic leg ulcer**. Do you have time to volunteer to help us do this? We are also developing a new guideline on **the management of psoriasis and psoriatic arthritis in adults** this year and are looking for lay representatives to become involved.

We are keen to hear from people who are affected by any of these conditions or who have an interest in these areas. Membership of a guideline development group provides an opportunity for patients' and carers' to help us identify the issues that are important to them so please help us to get people involved.

Don't have the time to commit to group meetings? Why not send in some patient and carer issues of concern you think the above guidelines should cover? If you think you could help us involve patients and carers in any way, please get in touch.

Do you have time to review a guideline?

Interested in sexual health? SIGN is currently reviewing a clinical guideline on **management of genital Chlamydia trachomatis infection**. This guideline is due to go out for consultation in April and we are putting together a list of people who could review the draft guideline. If you would be interested in doing this, please let me know.

New provision of information section in SIGN guidelines

If you have read or reviewed any of our guidelines you will know that each guideline has a section on "information for discussion with patients and carers". These sections vary in scope and tend to relate to the remit of the guideline and the issues identified as being of concern to patients and carers.

We have been thinking of ways to try and improve this section. Healthcare professionals and patients have suggested that we need to be clearer who the target audience of this section is and what

we are trying to achieve. To help clarify this, this section aimed at healthcare professionals will be standardised to include:

- feedback from any focus groups or interviews we have held with patients and carers;
- a checklist for provision of information (this will advise clinicians on what information should be discussed/provided at various stages of the patient journey. Direct feedback from patients and carers, evidence from the guideline and the experiences of the clinicians on the guideline development group will inform this checklist); and
- further sources of support and information.

The title of this section will change to “provision of information”. The first guideline to contain this information in its new format will be the guideline on management of hip fracture which is due to be published in August. If you would like to see this new format earlier, you could take part in the peer review of Chlamydia in April!

Better Cancer Care – The Scottish Government want to hear from you!

Significant improvements have been made in the quality of cancer care since the launch of the Scottish Cancer Strategy in 2001 – Cancer in Scotland: Action for change. However, there is still room for improvement. A national discussion has been launched to help inform the development of a new action plan to build on achievements and to identify priorities in tackling cancer in the years ahead. The Scottish Government is keen to hear the views of patients, carers and members of the public. If you are interested in commenting you can download the document from www.scotland.gov.uk/Topics/Health/health/cancer or you can request a hard copy by phoning 0131 244 5108.

You can get involved in the discussion by:

- completing and returning the feedback form at the back of the report (also available on-line at www.scotland.gov.uk/Topics/Health/health/cancer)
- participating in one of the discussions planned across Scotland (details available from www.scotland.gov.uk/Topics/Health/health/cancer)
- e-mail your comments to bettercancercare@scotland.gsi.gov.uk

Events organised by other people

The following events are not run by SIGN but are listed to share information and raise awareness. If you would like to attend one of these events, please contact the organisers directly.

Changing minds conference 2008 • 19th March Centre for Contemporary Arts, Glasgow

A one day event organised by the National Resource Centre for Ethnic Minority Health's (NREMh) mental health and well-being programme. It provides delegates with the opportunity to learn about recent work with black and ethnic minority communities.

NREMh would like to encourage users and carers with an interest or involvement in the mental health and well-being of black and ethnic minority communities to attend. For more information, contact Ruairi O'Brien on 0141 354 2900 or e-mail nrcemh@health.scot.nhs.uk

No place like home: Child support conference • 19th March The Lighthouse, Glasgow

This one day conference organised by Shelter Scotland, will look into meeting the needs of children and families who are homeless or experiencing housing problems.

Shelter Scotland's Family Projects provide advice, practical and emotional support to families in these situations. They have developed a model of good practice and therapies in art, play and drama to help children cope with this difficult time in their lives.

For more information visit <http://scotland.shelter.org.uk> or phone 0844 515 2483.

Health awareness

World Kidney Day • 13th March

Each year the International Society of Nephrology and the International Federation of Kidney Foundations work together to raise awareness of the prevention and treatment of kidney disease. If detected early chronic kidney disease (CKD) can be treated and further complications are reduced. If you would like to read more about World Kidney Day you can visit www.worldkidneyday.org Did you know that SIGN is currently developing a guideline on diagnosis and management of chronic kidney disease? This guideline is due to be published in March. If you would like to pre-order copies, please phone 0131 718 5090.

Depression Awareness Week • 21st - 26th April

Depression awareness week aims to raise the profile of depression and helps to raise money for services. The theme this year will be “employment”. Depression Alliance has many opportunities for you to become involved. Perhaps you would like to help raise awareness of depression by displaying a poster within your organisation? Or if you suffer from depression, you could share your story with them? For more information visit www.depressionalliance.org

SIGN is currently developing a guideline on non-pharmacological management of depression. The guideline development group is considering the evidence around lifestyle and self directed interventions, complementary therapies and psychological therapies.

Pitter patter of tiny feet at SIGN

Some of you know that I am expecting my first baby in March and I'm due to go on maternity leave at the end of February. We are currently recruiting a new member of staff to take over my post for seven months and continue with all projects I have been working on. I trust that you will continue to comment on drafts, help with recruitment of lay representatives, assist with the promotion of SIGN and maintain a general interest in our work. I look forward to working with you all again when I return to SIGN in October for a rest!



Goodbye Louise

Louise Phillips is leaving SIGN in April to return to her home in Australia. She has been with SIGN since April 2007 and has worked with me on many aspects of patient/public involvement. Many of you will know Louise from various events you have attended such as Voices for all, patient representative discussion days or you may have met her when you visited the SIGN stand at one of the shopping centres. Louise will be missed at SIGN for her enthusiasm, commitment and efficiency as well as her homemade lamingtons! (sponge fingers dipped in chocolate with desiccated coconut) Thanks for all your hard work Louise and we wish you all the best for the future!

Help us to save the environment

Do you receive this newsletter by post but have an e-mail address? Why not help us to reduce the amount of paper we use by providing us with your e-mail address? By doing this you will receive the newsletter electronically the same day as it's published! Please also let us know if your contact details are about to change – we don't want to lose you!

Best wishes